WHEN YOUR BEST EFFORTS FAIL
by
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WHEN YOUR BEST EFFORTS FAIL...

An Open Letter to Eye Specialists

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Dear Doctor:

Although your work is directed and your life dedicated to the preservation of sight, the time will come more than once during your career when you will face the unpleasant fact of certain and irremediable blindness in a patient of yours. It is at such a time, when the vast store of scientific knowledge and healing skill which you command have not sufficed to stem the loss of sight, that you have, for that patient, the greatest service yet to render.

To an overwhelming degree, his first steps toward some adjustment to blindness will be guided by you. His high respect for your calling, his desperate dependence on your professional skill, and his trust in you as a friend in need will already have made you, willingly or not, a strong influence in those many areas of his life affected by his eye condition. Willingly or not, you will carry a great share of the responsibility for his actions and reactions immediately subsequent to the diagnosis of permanent blindness. Whether those first steps are directed along the road to independence and self-sufficiency, or toward the bog of idleness, self-pity, and eventual helplessness, will depend to an uncomfortably great extent on your handling of his case after your best medical and surgical efforts have failed.

It is the sincere desire of the National Federation of the Blind to be of assistance to you in this challenging area of your professional life. From the collective experience of the independent, self-sufficient blind persons who make up the Federation's membership, we offer you on the following pages a discussion of the nature of blindness, of the achievements of the blind, and of specific aspects of the doctor-patient relationship which significantly influence adjustment to blindness. It is our hope that this discussion may serve, in some measure, to supplement your scientific knowledge of the structure, function, and pathology of the eye with a greater understanding of the needs, problems, and potential of the newly blind, and a comfortable, positive, effective approach to blindness or oncoming blindness in your own patients.

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Blindness is by no means a disabling physical handicap. Thousands of independent, self-sufficient, happy blind persons, from every walk of life, in every type and at every level of competitive employment, and representing every degree of physical and intellectual ability, have already proved this beyond a shadow of a doubt.

There are blind professors teaching in our colleges and universities, and

blind teachers in our public schools. Blind scientists are contributing valuable research to our national defense program and to private industry. Blind lawyers are arguing and winning cases in court, carrying on legal research, and representing government agencies in the civil service. Blind businessmen are holding their own with sighted competitors in winning the buying public.

Skilled blind craftsmen are operating standard machines and meeting the exacting requirements of private industry. Blind mechanics and technicians are helping to keep our engines and picture tubes operating. Blind stenographers and switchboard operators are assisting communications in private and public offices. Blind counselors and social workers are handling clients and red tape on a par with their sighted counterparts. And blind housewives are cooking dinners, ironing shirts, changing diapers, and pacifying husbands with usual feminine success.

There is no longer any reason, if ever there was, for the air of utter tragedy which has generally accompanied the loss of sight -- no reason, that is, beyond the public stereotype of the helpless, hopeless blind, the long-established tradition of charity to the blind, and the widespread lack of knowledge of the achievements of the blind. For, given adequate special training in the practical skills of daily living, and the thoroughly implanted belief that blindness need not bar anyone from a normal, productive existence, your newly blind patient can be expected to achieve, not cheerful resignation to a seat on the sidelines of life, but the ability to remain a capable, independent, fully-participating member of society, competing in work and play on equal terms with his sighted neighbors.

Perhaps a brief history of a small group of blinded adults will serve to reinforce the point. All were students for a short period at an excellent orientation center for the blind in a large western city. One of them was an electrician, blinded in a home workshop accident; another, a long-time school teacher who had suffered a detached retina in her one good eye. A third was a bright girl who had been forced to drop out of junior college several years before entering the center because of failing sight due to the development of cataracts secondary to severe congenital myopia. The fourth, a young man of extremely limited intelligence, had been near-blind since birth, and had come to the center from the state school for the blind where his educational achievements were slight.

The latter, whose remaining vision was negligible, was the first student admitted by the center and received a great deal of individual attention. At the end of his rather prolonged stay, he was helped to secure employment as a turret lathe operator in a small factory manufacturing auto parts. He is still there, operating his machine in competition with sighted employees and performing to the full satisfaction of his employers. He travels independently to and from work, and is dependent on no one for his personal needs. By saving his money regularly he was able to purchase a house which he has subsequently rented out to finance the purchase of a second one. As a wage earner and a property owner, he has more than repaid in taxes the cost of his education and orientation, and his accomplishments have exceeded the most optimistic expectations of society for sighted adults of comparably low intelligence.

The more intellectually favored junior college student, who had long since

given up hope of pursuing her education further, or of attaining the universal feminine goals of marriage and family, came to the center in its early days under the impression that it was a home for the blind where she might live out her days in protective custody. She was electrified to discover, her first day there, that the center's director was himself blind, and that he, like thousands of other blind persons, was a college graduate.

From that moment her concept of herself and her potential underwent a drastic change, and after a few months spent acquiring basic skills in braille, typing, and cane travel, she entered the state university, from which she graduated, three years later, with honors and a Phi Beta Kappa key. While in her first graduate year she married a fellow graduate student, and is now a highly competent housewife and mother of a lively three year old girl. Her cooking, self-taught after marriage, with no previous experience or instruction, enjoys a high repute among blind and sighted friends alike. Between the stove and the diapers she has managed to write a book about her experiences at the orientation center and the university and is seeking a publisher with some hope of success.

The blinded electrician, despondent and full of self-pity when he entered the center, was sure that his days of usefulness were over. Within a few weeks he was considering seriously the possibility of returning to the world of gainful employment, and soon after became convinced that his own field was not closed to him.

Totally blind, he is now, as he was before, a journeyman electrician, working out of the union hiring hall, earning union scale wages, and, according to his hard-headed contractor employers, competing in quality and quantity of work on a par with his sighted co-workers. The adaptations in tools and techniques which he requires to operate efficiently without sight are few and simple. Almost all of them he has devised himself. His experiences as an electrician after the onset of blindness have included work on a project in which an entire three-bedroom house was completed in five days, with workmen of all types completing their respective tasks at the same time, and a civil service examination during which he found it necessary to correct the chief examiner in a point concerning the interpretation of an electrical blueprint.

The school teacher, partially blind when she entered the center, had been told by her ophthalmologist that she could become a dictaphone-typist, since he had heard that blind persons could do this and she had once done office typing many years before. This recommendation was incorporated into her medical report and was later echoed by a counselor of the state department of vocational rehabilitation. Reluctantly she had accepted the idea as her one chance to remain in the ranks of the employed.

The skillful training and positive philosophy of the orientation center, however, led her to question the necessity of this seemingly hopeful and logical vocational reassignment, with the result that she returned to her school district the following year and resumed her teaching. When, a year later, her retina detached completely, and she found herself totally and permanently blind, she took a short leave of absence, reorganized her methods and materials somewhat, and returned

again, this time for good, to her fourth grade classroom. Recently rehired for the fourth year, she now has tenure in her district. Many parents of fourth graders request that their children be placed in her class because of her growing reputation for developing responsibility and self-direction in her students.

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These people are not exceptional. Their accomplishments are not unique, nor even particularly remarkable. More amazing by far is the fact that while they, and thousands of their fellow blind, are living and working on equal terms with their sighted counterparts, the vast majority of persons still consider blindness a fate worse than death; still regard the blind as miserable, helpless, inferior creatures, doomed to live out their lives in a lonely "world of darkness" and dependent forever on the charitable ministrations of their more fortunate sighted brothers; still donate thousands of dollars to "recreation centers," sheltered workshops, and outstretched tin cups; still define "adjustment" to blindness in terms of the ability to produce a smile of contentment and gratitude to a beneficent society from the shelter of a rocking chair.

Blindness need be at worst a physical nuisance. Because of mistaken public attitudes, unfortunately, it continues to be a great social and economic handicap. To overcome both the physical nuisance of blindness itself, and the effects of public misconceptions about it, as thousands of capable, self-supporting blind persons have already done, your newly blind patient -- child or adult -- will need to acquire three things: (1) a complete acceptance of his blindness, (2) an unshakable confidence in the ability of the blind, and of himself as a blind person, to live a normal life and to support himself in competitive employment during his productive years, and (3) a thorough mastery of the basic special tools and skills, including braille and cane travel, which will enable him to operate normally without vision in a sighted world.

Your role in helping to insure his acquisition of each of these things is an all-important one, for from your approach to his blindness he will take his cues to the severity of his handicap and the extent of his limitations. Your attitudes and your behavior toward him, from the moment his blindness is certain, can either reinforce or begin to overcome his own feelings of helplessness and despair. It is one of your gravest professional responsibilities and unquestionably one of your finest professional achievements to initiate the process by which your newly blind patient will be enabled to take his place once more as a normal, contributing member of society. In the following section we shall discuss at length those specific areas in which you, as an eye specialist, can make your most dynamic and most effective contribution to this cause.

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EARLY DIAGNOSIS: One of the most obvious but crucial elements that contribute to a real acceptance of blindness is the certain knowledge that sight cannot be restored. Examples are numerous of helpless blind men and women, living in complete dependence upon their families and the social agencies while waiting -- sometimes for years, sometimes for a lifetime -- for an operation, a new drug, or the normal healing powers of nature to bring back their vanished vision. Their faith in the future restoration of their sight is matched only by their pitiful uselessness to themselves and to society.

Perhaps even more pitiful are the parents of blind children -- particularly the partially blind-- who chase frantically and unceasingly from clinic to doctor to fraudulent quack, squandering their savings in the vain attempt to make their offspring "normal," and seriously jeopardizing, thereby, their children's very real chance for normal personality and normal achievement through appropriate special education and training.

It is terribly, vitally important that your patient be informed at the earliest possible moment and in the most absolute and unequivocal terms -- just as soon as you yourself are reasonably sure -- that he is blind, about to become blind, or in danger of going blind in the future, and that his blindness is or will be permanent and irremediable. It is not half so cruel to state the truth quickly and positively, nor one-tenth so damaging to the personality or the psyche of the average patient, as it is to prolong the anxiety-ridden months of unresolved doubt and fear and wondering, or to leave room for lingering, idling, fruitless hopes of regaining sight.

Adjustment to blindness must inevitably be preceded by acceptance of the fact of blindness. It is entirely natural that most persons accept this fact with great reluctance and with great difficulty. It is equally natural and reasonable that most cannot accept it until they hear it directly and unequivocally from their eye specialist.

A strong plea must be made here also for a correspondingly frank and direct statement to the patient with low vision, and again especially to the parents of a partially seeing or partially blind child. Such patients need and have a right to be kept informed of their current visual status, to understand as completely as possible the nature and extent of their deviation from the visual norm and the relative change in vision from examination to examination. The tendency of most persons with slowly decreasing vision -- both children and adults -- is to ignore or even to try to conceal their loss. More than a few, in fact, may even be unaware that they are seeing less, and generally achieving less, each year. Only you can tell them the truth and be believed.

No more persuasive argument for the necessity and the desirability of an early and forthright statement to the patient can be offered than the following accounts of two actual cases within the author's direct knowledge.

On a certain evening I had been privileged to address an association of ophthalmologists on the subject of the education of blind children in the public schools. During the course of the talk I stressed, as here, the importance of a direct, unequivocal statement to parents of children who are blind or face the prospect of blindness in the future.

The following day I received a call at school from the mother of a legally blind four-year old boy, inquiring about educational facilities for him. During a subsequent conversation with her I learned that he was the patient of the president of the ophthalmological association who, on the morning following my talk, had told the mother for the first time that her child was blind and would remain so.

"It was such a relief to finally learn the truth," she told me. "For four

years we've been worrying and wondering, but we could never get a definite answer from the doctor. He just kept telling us to wait and see. Now that I know my boy is blind I can stop wondering what the trouble is and start doing something about it."

Her call to the school had been the first step.

On another occasion I was discussing with the blind college student whose story was related earlier her experiences with approaching blindness.

"If I had only known from the beginning," she stated repeatedly, "that I was blind and that it didn't mean the end for me, my adjustment and my preparation would have begun much sooner and I would have saved ten years of useless, fearful waiting.

"I blame the ophthalmologists wholeheartedly. I must have seen twenty of them, and not one ever even mentioned blindness, though I was probably legally blind since childhood. They offered nothing, no real indication of just how bad my sight was, no information about people or agencies that could help me, no idea at all of the blind and their place in the world. All I got was non-recognition of blindness and its implications, and the eternal, useless hope of sight restoration.

"We were all ignorant, my family and I. The ophthalmologists were the only authority we knew and we trusted them completely. If they had only told me that the blind could do things...."

INFORMED ENCOURAGEMENT: An early, blunt, and final diagnosis of blindness undoubtedly represents for most of you a difficult and painful task. Perhaps the initial shock, despair, and bitterness of previous patients to whom you have imparted such disheartening tidings has convinced you that the "sledgehammer" approach is too traumatic for both you and patient, and that the extension of hope can soften the final blow through a gradual rather than sudden realization by the patient that his active, useful days are over. It goes almost without saying that your task becomes much easier and your role much clearer when you know that your newly blind patient need not, indeed with your help will not, resign himself to inactivity and uselessness; that as you inform him of his blindness you can extend a very real hope, not of normal sight but of a normal life without it. If it is vitally important that the diagnosis of blindness be made early and definitely, it is indispensable that the diagnosis be accompanied by a sincere, positive, and equally unequivocal message of informed encouragement.

It is your humanitarian responsibility, if not your professional duty and your moral obligation, to tell your newly blind patient in no uncertain terms that blindness is not the end for him, that thousands of blind persons like him, many of them also newly blind, have learned to operate with complete independence, to achieve on a basis of complete equality, and to live completely normal, productive, happy lives in our predominantly sighted society.

You must steel yourself to avoid pity, apology, or the implication of inferiority because vision is gone. Your patient will face those soon enough and often enough when he leaves your office. You must train yourself not to offer

half-hearted hope, the prospect of an "almost normal" existence and of second-class citizenship. You must convince yourself, so that you can convince your patient, that blindness is not a tragedy, not an incapacitating affliction, not a bar to anything that makes life worth living, but a purely physical nuisance, already overcome by thousands, and capable of being overcome by anyone. You must guard against imposing restrictions of any kind, other than those made absolutely necessary by some eye pathology, lest you reinforce the erroneous but widespread belief that blindness in itself necessarily limits movement or activity.

Above all you must cite the achievements of the blind today: the students, the scholars, the teachers, the scientists, the lawyers, the businessmen, the skilled mechanics and craftsmen, the nurses, secretaries, and housewives who offer living proof that the hope you offer is not a vain palliative, that opportunities for successful achievement without sight are as numerous as the categories of human activity. And whether your patient be a child in school, an able-bodied worker in his full productive years, or a faltering nonagenarian, you must urge without cease the goals of self-respect, self-sufficiency, and activity normal to his station in life.

"We were all ignorant, my family and I." It could have been any one of thousands of blind persons speaking. "The ophthalmologists were the only authority we knew and we trusted them completely. If they had only told me that the blind could do things...."

In your confident, positive, unapologetic, unsentimental approach to his blindness and to blindness in general lies your newly blind patient's first hope of accepting and overcoming his lack of sight, and, let us admit, your last hope of personal satisfaction from the handling of his case.

SOUND REFERRAL: Once you have told your patient he is blind, and convinced him that "the blind can do things," you have but one major service left to render. That is the essential task of providing him with information about or putting him in actual contact with those agencies, services, organizations, and individuals which can help him to take his place as soon as possible as a normal, confident, capable member of society. Most newly blind persons do not know what help is available to them in their struggle for independence and self-sufficiency. It is well within your power, surely even within the scope of your professional responsibility, to keep informed about such vital services as residential and public school programs of education for blind children, orientation or rehabilitation centers and home teacher-counselors for blind adults, the regional or state offices of the Bureau of Vocational Rehabilitation, aid to the blind and other social welfare services, the braille and talking book library service of the Library of Congress, and the important achievements of the National Federation of the Blind and its state and local affiliates.

It is likewise incumbent upon you, as the first and most respected source of information for your blind patient, to be aware of deficiencies in the philosophy and practices of both public and private agencies for the blind, many of which are not yet operating on the principle that the blind are capable of both normal personality and equal competitive achievement in sighted society, and some of which,

indeed, are seemingly dedicated to fostering the opposite view. It is imperative that your newly blind patient, usually still doubtful and dependent, not be referred to one of the latter organizations -- the recreation centers, sheltered shops, and "sunshine societies" -- whose main purpose, only too clearly revealed in their pity-inspiring, bleeding-heart fund raising campaigns, is to alleviate some of the wretchedness, assuage some of the loneliness, and occupy the idle hours of a group of unfortunates denied access to the normal pursuits of society by a cruelly disabling affliction, one which robbed them of the capacity to compete for a living, but which apparently left them with just enough resources to weave a basket, sing a song, or consume a moderate supply of coffee and cake under kindly sighted supervision. Even a few weeks under the benevolent wing of one of these "idle-hour" societies may be enough to convince a healthy former wage earner that his previous estimation of blindness was correct, and that though he may learn to do a few things for himself, he would be absurd to entertain the thought of competing with those advantaged by normal sight, especially when there are so many kind people willing to devote their time to helping and amusing him.

Your newly blind patient, like his thousands of predecessors, will find it exceedingly hard to believe that he can compete on equal terms, even harder to accept the idea that he should compete without sight. He will need assistance, and he will need it quickly. Upon you, as a trusted professional advisor, must necessarily devolve the obligation not only of knowing but of evaluating the many kinds of assistance available to him, and of helping him to select and secure only those services which will further his progress along the road to independence and self-sufficiency.

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This, then, is the potential force for good which you, the eye specialist, represent, even after your medical skill has not sufficed to preserve or restore sight. If you can honestly tell a patient he is blind, if you can believe, and make him believe, that blindness will not bar him from a normal life, if you can guide him quickly to those services which will equip him for normal life without sight, then your contribution to society will not be limited to the saving of sight, magnificent as that contribution alone may be -- and, for that small but most worthy segment of the population which is constituted by the blind, your best efforts shall not fail.

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